



2017 Annual Report

Letter from the President

Dear Friends,

2017 has been the most productive and successful year to date for the Mowat-Wilson Syndrome Foundation! The Board of Directors has worked tirelessly for over two years to host the 2017 Mowat-Wilson Syndrome Foundation International Family Conference in Washington, DC last June. The Conference exceeded all of our expectations and family feedback was incredible!



Suffice it to say, it was quite the program and there were many, many people that made it happen---including, but not limited to, all of the conference speakers, workshop leaders, volunteer photographers and their assistants, audio-visual contractors, child/adult care workers, hotel staff, the board of directors, family volunteers and family speakers, musicians, and special needs vendors. It was an incredible effort and very much appreciated!

We had a tremendous turnout of families from the Mowat-Wilson Syndrome community that included people from 7 different countries and 32 states! The conference was live-streamed on Facebook and all of the lectures and workshops were posted on our website, www.mowat-wilson.com, for those families that were unable to attend in person.

We are also very proud of the MWSF PEER Patient Registry that we maintain in partnership with Genetic Alliance. In 2017, there are three MWS specific surveys that were available for families to share their data. In 2018, the MWS Growth Chart survey, in conjunction with researchers, will be available. It will be an invaluable resource for physicians treating patients with MWS.

As I handed the office of President back to Deby Curry last October, I wanted to express my deep appreciation to my hard-working, selfless, all volunteer Board of Directors! Our mission is supporting this incredible community and I hope that you will be encouraged join us in any or all the following ways:

- Sign up for the PEER Patient Registry and SHARE YOUR DATA
- Sign up for the MWSF periodic newsletter
- Join our social media channels
- Volunteer at a MWSF event
- Join a committee
- Make a donation
- Help us fundraise

Much love to all of our families touched by Mowat-Wilson Syndrome,

Susan Triunfo
2017 President



15

Speakers including
Dr. David Mowat and
Dr. Meredith Wilson

158

Adults including
parents, caregivers and
professionals

11

Countries

80

FAMILIES
Affected by MWS
attended the
conference

44

MWS patients

32

US states

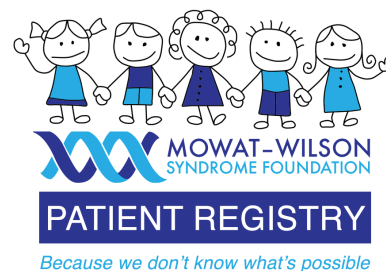
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Siblings





Share your data... please.



As of March 1, 2018, the Mowat-Wilson Syndrome Patient Registry has over 133 participants involved at varying levels with the three current surveys. With the launch of the **Growth Data Survey** we hope to be able to provide the valuable information necessary for the development of Mowat-Wilson Syndrome specific growth charts.

"Participating on the MWS Patient Registry was a lot easier than I thought. Sharing the information of our children is crucial to educate doctors and researchers about MWS", said Laura Chrysostomo, mother of Bella, a 15 year old girl with MWS.

130+

Over 130 families have shared data in the MWS Patient Registry



Research for a Better Life. Your Data Matters!

The mission of The Mowat-Wilson Syndrome Foundation is to enhance the lives of people affected by Mowat-Wilson Syndrome by providing family support, raising awareness, and supporting research and education.



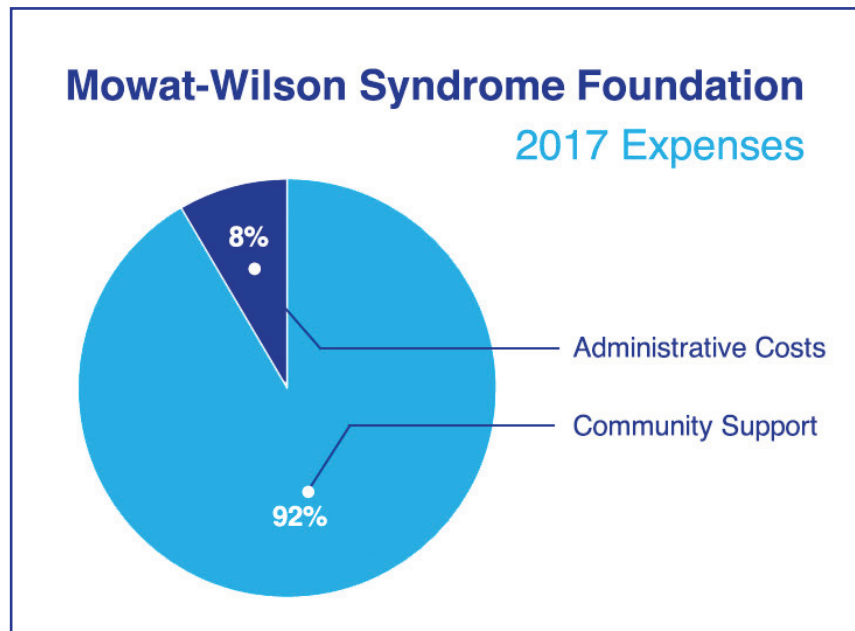
250

Social media cards provided to the families to raise awareness about Mowat-Wilson Syndrome



Mowat-Wilson Syndrome Foundation

2017 Financials



Mowat-Wilson Syndrome Foundation

BALANCE SHEET COMPARISON

As of December 31, 2017

	TOTAL	
	AS OF DEC 31, 2017	AS OF DEC 31, 2016 (PY)
ASSETS		
Current Assets		
Bank Accounts		
1000 TOTAL BUS CHK (6107)	30,948.12	11,502.92
1001 Cash Reserved	0.00	45,000.00
Total 1000 TOTAL BUS CHK (6107)	30,948.12	56,502.92
In-kind donation clearing	0.00	0.00
Total Bank Accounts	\$30,948.12	\$56,502.92
Other Current Assets		
1050 Awareness Product Inventory	0.00	0.00
Total Other Current Assets	\$0.00	\$0.00
Total Current Assets	\$30,948.12	\$56,502.92
TOTAL ASSETS	\$30,948.12	\$56,502.92
LIABILITIES AND EQUITY		
Liabilities		
Total Liabilities		
Equity		
Retained Earnings	56,502.92	29,921.78
Net Income	-25,554.80	26,581.14
Total Equity	\$30,948.12	\$56,502.92
TOTAL LIABILITIES AND EQUITY	\$30,948.12	\$56,502.92

Mowat-Wilson Syndrome Foundation

2017 Financials

Mowat-Wilson Syndrome Foundation

PROFIT AND LOSS

January - December 2017

	TOTAL	
	JAN - DEC 2017	JAN - DEC 2016 (PY)
Income		
4000 Non Profit Income		387.32
4001 Corporate Donations	52,357.54	3,198.38
4002 Individual Donations	15,982.34	37,209.76
4400 2016 Seattle Medical Forum Registration		4,200.00
4401 2017 MWSF DC CONFERENCE	37,010.40	
Total 4000 Non Profit Income	105,350.28	44,995.46
4100 Sales-Promotional/awareness products		589.95
4402 2018 Concert Sponsor	1,050.00	
In-kind donation		424.11
Sales of Product Income	162.75	
Sales-Promotional/awareness products (t-shirts, pens, lapel pins, rubber bracelets)		230.40
Total Income	\$106,563.03	\$46,239.92
Cost of Goods Sold		
4101 Cost of Goods Sold		275.20
Total Cost of Goods Sold	\$0.00	\$275.20
GROSS PROFIT	\$106,563.03	\$45,964.72
Expenses		
5001 2016 Seattle Medical Forum		8,343.62
5002 2017 MWSF Conference	120,473.91	
6000 Bank Charges	980.51	311.92
7000 Memorial flowers	112.69	
7010 Office Expenses	238.64	65.95
7020 Office/General Administrative Expenses	1,500.09	1,555.40
7030 Promotional		2,366.23
7031 Fundraising Expense	6,000.00	147.36
Total 7030 Promotional	6,000.00	2,513.59
7050 Research funding		5,000.00
7060 MWSF Peer Patient Registry	331.50	
8010 Insurance - Liability	660.00	794.00
Dues & Subscriptions	75.00	75.00
Labor or services donated		624.10
Legal & Professional Fees	1,100.00	
Stationery & Printing	595.49	
Taxes & Licenses	50.00	75.00
Total Expenses	\$132,117.83	\$19,358.58
NET OPERATING INCOME	\$ -25,554.80	\$26,606.14
Other Expenses		
Miscellaneous		25.00
Total Other Expenses	\$0.00	\$25.00
TOTAL		
	JAN - DEC 2017	JAN - DEC 2016 (PY)
NET OTHER INCOME	\$0.00	\$ -25.00
NET INCOME	\$ -25,554.80	\$26,581.14

2017-2018 Officers & Board of Directors

President

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Vice-President

Karen Baer

Secretary

Katie Fineberg

Treasurer

Susan Triunfo

Directors

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Laura Chrysostomo

Sandie Flannery

Al Triunfo

Lori Linn

John Sell

Wendy Sell

Catherine Tolman

Medical Advisory Board

Meredith Wilson, MD

Clinical Associate Professor
CHW Department of Clinical Genetics
The Children's Hospital, at Westmead Hawkesbury
Rd., & Hainsworth St. Westmead NSW

Margaret Adam, MD, FAAP, FACMG

Associate Professor of Pediatrics
Division of Medical Genetics
University of Washington School of Medicine

Jose M. Garza, MD, MS

GI Care for Kids
Medical Director, Neurogastroenterology and Motility
Children's Healthcare of Atlanta

Jay L. Vivian, Ph.D.

Research Associate Professor in the Department of
Pathology and Laboratory Medicine
Scientific Director in the Transgenic Facility and
Gene Targeting Institutional Facility
University of Kansas Medical Center

David Mowat, MBBS, MRCGP, DRACOG, FRACP

Senior Staff Specialist
Clinical Geneticist
Sydney Children's Hospital

Merlin Butler, MD, PhD, FFACMG - Chair

Professor of Psychiatry, Behavioral Sciences and Pediatrics
ABMG Certified Clinical Geneticist and Clinical Cytogeneticist
Departments of Psychiatry & Behavioral Sciences and Pediatrics
Kansas University Medical Center

Belinda Dickie, MD, PhD

Assistant in Surgery, Co-Director
Colorectal and Pelvic Malformation Center
Pediatric Surgeon
Assistant Professor, Harvard Medical School

John M. Schreiber

Child Neurologist, Neurophysiologist, and Epileptologist
Children's National Health System and Pediatric Specialists of
Virginia.